



Family High Risk Program 1983 – 1999

Utah Department of Health
Chronic Disease Genomics Program
Assessment conducted October 2003 – April 2004

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Assessment of the Family High Risk Program

The following individuals were invaluable in developing the report. They generously donated time and talent in helping to complete the assessment of the Family High Risk Program (FHRP). Their professional insight provided direction for future recommendations and without their continued support and generosity, the report would not be possible. Below is a brief description of their role in the FHRP. There are others who also played a role in the development of the report but are not identified specifically in this section. Interview dates for all individuals can be found in Appendix A.

Jenny Johnson *Health Program Specialist, Chronic Disease Genomics Program, Utah Department of Health*

Jenny Johnson developed and conducted the assessment of the FHRP. She was also responsible for contacting former FHRP staff and other key players for interviews during the assessment. Jenny compiled the report, developed future recommendations for family history programs, coordinated and facilitated a one-day meeting with key players and representatives from the Centers for Disease Control to discuss the report and recommendations, and wrote and distributed the meeting proceedings and final version of the FHRP report to those involved with the assessment.

Joan Ware *Program Manager, Heart Disease and Stroke Prevention, Utah Department of Health*

Joan Ware was instrumental in developing the FHRP. Her vision of its potential as an intervention to help families at high-risk for disease, along with that of Roger R. Williams, M.D., was crucial in the development of partnerships between state and local entities. She was involved with the program since its inception and was heavily involved in developing the interventions, school curriculum, follow-up studies, and other program materials. With over 25 years of experience working in public health, her insights and experiences have proved invaluable in helping to piece together the report and recommendations for future family history projects.

Karen Coats *Program Coordinator, Heart Disease and Stroke Prevention, Utah Department of Health*

Karen Coats served as Director for the FHRP for a number of years until the program ended in 1999. Her experiences with the program have helped identify the most recent barriers with implementing this type of project into public health again. She has also been able to provide documents from the program that would have otherwise been lost due to the length of time since the program was running. Karen worked closely with Joan Ware to complete the program assessment and was extremely helpful in documenting the logistics of the FHRP, as well as providing recommendations for the future.

Rebecca Giles *Program Manager, Asthma and Chronic Disease Genomics Programs, Utah Department of Health*

Rebecca Giles provided direction and insight into the development process of the assessment. With over 17 years of experience in public health, her knowledge and skill with developing this type of evaluation and report was extremely valuable. Rebecca also served as Director for the FHRP for a few years in the late 1980's and has provided documents and insight, especially with piecing together the evaluation methods and processes.

LaDene Larsen *Bureau Director, Health Promotion, Utah Department of Health*

LaDene Larsen has been a leader in integrating genomics and family history into public health practice for over 23 years. Her leadership qualities have been instrumental in developing the Chronic Disease Genomics Program, which was charged with the task of assessing the FHRP. She provided assistance with the development of the assessment tool used to evaluate the program as well as technical support with the report.

Ted D. Adams *Professor, Departments of Family and Preventive Medicine, Physical Therapy, Exercise and Sports Science, and Food Science and Nutrition; Program*

Director for Fitness Institute, LDS Hospital; Cardiovascular Genetics, University of Utah

Ted Adams was instrumental in the development of the report. He generously provided program documents from University of Utah Cardiovascular Genetics Research Clinic (UCVG) to help identify current barriers to implementing this type of risk assessment tool again. Dr. Adams also provided expertise in determining how to comply with the Health Insurance Portability and Accountability Act (HIPAA) regulations and other applicable laws. His experiences working with high-risk families from the Health Family Tree project have provided valuable insight into what a future program should look like in order to address the same barriers.

Steven C. Hunt *Professor, Department of Internal Medicine, Cardiovascular Genetics, University of Utah*

Steven Hunt has been a leader in the development of the HFT Questionnaire and FHRP for the past 20 years. He, along with other team members from UCVG, has continually advocated the use of the instrument as a way to enhance current public health programs and messages. Dr. Hunt was extremely helpful in the development of the report and has provided past HFT data and statistics to further show the importance of the program as a way to identify families at high-risk for disease.

Paul N. Hopkins *Professor, Department of Internal Medicine, Cardiovascular Genetics, University of Utah*

Paul Hopkins has been involved with UCVG for 20 years where he continues to be actively involved in a number of research programs devoted to finding and understanding the reasons that premature heart attacks and strokes occur in high-risk families and to use this knowledge to promote preventive intervention in these families. He worked closely with Drs. Adams and Hunt to promote the use of the HFT as a tool to accomplish these goals.

Richard E. Gress, *Computer Professional, Cardiovascular Genetics, University of Utah*

Richard Gress provided both UCVG and the Utah Department of Health (UDOH) with technical assistance in interpreting past HFT statistics and data.

Robert M. Chamberlain, *Ashbel Smith Professor of Epidemiology; Deputy Chair, Department of Epidemiology; and Director, Cancer Prevention Education, University of Texas M.D. Anderson Cancer Center*

Robert Chamberlain developed the HFT with colleagues from the Baylor College of Medicine in the early 1980's. He was instrumental in understanding the development of the FHRP and the collaborations between the University of Utah UCVG and the Baylor College of Medicine. Dr. Chamberlain was a delight to work with and has identified the original intent of the HFT as well as the benefits and barriers of using a family history tool to target public health messages and interventions.

Mike Friedrichs, *Lead Epidemiologist, Bureau of Health Promotion, Utah Department of Health*

Mike Friedrichs worked as the Information Analyst for the FHRP from 1989 until 1999. His involvement in distributing the follow-up studies helped to clarify the process of evaluating behavior change in high-risk families. He has also been helpful in determining future evaluation methods for similar intervention programs and interpreting past program data.

Elvin Asay, *Alaska Department of Health and Human Services*

Elvin Asay worked as the Information Analyst for the FHRP until 1989. His input about the program helped to clarify the original method of evaluation, although this method was later altered due to lack of funding. He also provided program materials to help understand the logistics of the evaluation process, as well as that of the program itself.

Lyle Odendahl, *Assistant Attorney General, Utah Department of Health*

Lyle Odendahl provided insight into the legal issues program planners would have to face when designing a similar intervention project. He also helped to identify what information would need to be added to the original parental consent form as well as what process the consent form would need to take in order to receive Institutional Review Board and UDOH approval.

Sue Hall, *Vice President and Senior Consultant, Transformational Consultants International, Inc.*

Sue Hall was the Director of the FHRP from 1983 to approximately 1986. She generously donated time to help clarify the working relationships between staff from the UDOH Cardiovascular Program and UCVG. She was also helpful in identifying program background, theories behind intervention methods, national and state recognitions given to the program, and justification for doing the program in the future.

Susan Beck, *Associate Professor, College of Nursing, University of Utah*

Susan Beck was a staff member in the FHRP from 1984 until approximately 1986. She provided professional guidance in determining the appropriate changes a similar program would have to go through in order to be successful. Her background in nursing and cancer research has also provided insight into the types of interventions, evaluations, and nursing protocols that would need to be developed in conjunction with future projects.

Lori Ball, *Case Manager, Office of Managed Care, University of Utah*

Lori Ball was a former Director of the FHRP. Her professional background working with families and youth has helped to identify possible barriers in intervening with high-risk families via the school setting. She also identified possible past and future barriers for the FHRP, in terms of both funding and logistics.

Hal Hale, *Health Education Department, Jordan High School*

Hal Hale has over 20 years of experience teaching health education courses at the high school level. He was involved with the FHRP from the pilot phase until its demise in 1999. He provided valuable insight into the perception of the project from an educator, student, and parent/guardian's viewpoint and identified possible concerns for each group.

Russ Lauber, *Health Education Department, Brighton High School*

Russ Lauber has over 20 years of experience as a health educator and has been an advocate of the FHRP for nearly that same time. He provided direction and recommendations for future implementation of the project into the school systems. He also helped to identify possible barriers with regards to the Federal Educational Rights and Privacy Act laws and privacy issues that impact school districts. Russ continues to support this type of hands-on activity and eagerly awaits the return of similar programs.

Christin Sawyer, *Public Health Nurse, Weber-Morgan Health Department*

Christin Sawyer has worked as a public health nurse for nearly 20 years. She was involved with the Early Start for a Healthy Heart Program, a screening program for 3rd grade students and their families along the Wasatch Front at risk for high cholesterol. She was also involved with the FHRP and advocated its use throughout her community. Her experiences with counseling and providing interventions for high-risk individuals and families have helped to identify barriers within the local health department and school system.

Report on the Family High Risk Program

From 1983-1999, the Utah Department of Health (UDOH) teamed together with local health departments, the State Office of Education, local school districts, the Baylor College of Medicine, and the University of Utah School of Medicine Cardiovascular Genetics Research Clinic (UCVG) to collaborate on the Family High Risk Program (FHRP). The FHRP identified families at an increased risk of suffering from major chronic diseases that could be prevented, delayed, or treated effectively with early interventions.

Program “Champion”

The program began with the vision of Roger R. Williams, M.D., former director of the Cardiovascular Genetics Research Clinic and founder of Make Early Diagnosis to Prevent Early Death (MED PED), to create an accurate and reliable form of collecting and analyzing familial disease tendency. From a young age he was driven to understand and help those families at risk from premature death and disease. As a teenager, Dr. Williams had watched as his widowed neighbor raised her children alone because her husband had died suddenly at the age of 42. The most shocking thing about his death was that his family had expected it to happen; numerous other family members had died at young ages for apparently no identifiable reason. This devastated Dr. Williams and became the driving force behind his research in familial trends. Later he would research coronary-prone pedigrees, of which the first he studied and eventually diagnosed with familial hypercholesterolemia (FH) was his childhood neighbor’s family.¹

Dr. Williams’ research on coronary heart disease had shown that at the time of the FHRP approximately 5% of the Utah population contributed to 50% of the state’s total early coronary deaths (death before age 55).² Encouraged by these findings as well as other research on familial tendency as a major risk factor in coronary heart disease, Dr. Williams joined efforts in 1980 with Drs. Steven Hunt, University of Utah, and Robert M. Chamberlain, Baylor College of Medicine, to further develop the Health Family Tree Questionnaire (HFT). This health pedigree chart would later become the first step in the FHRP.

It is critical to understand the passion Dr. Williams had for the program. Built upon personal experience and years of research, he worked non-stop to develop tools to identify familial disease trends and help at-risk families. His thorough understanding of public health's core functions also aided in the success of the intervention component of the FHRP. Despite harsh criticism and a lack of support from national colleagues, he pushed ahead determined to prove the worth of the program. Unfortunately he passed away before national interest and support for family history programs could be generated. His death signified the end of the FHRP and as many commented during the assessment, the program was never the same after he died.

Partnerships and Collaborations

Partnerships played an important role in the FHRP throughout its 20 years of existence. Ironically the first critical partnership in the FHRP, between UCVG and the Baylor College of Medicine, was due to a chance encounter. Only after reading a small article in a Texas newspaper did Dr. Chamberlain learn of Dr. Williams' research on familial tendency of cardiovascular disease in Utah family pedigrees. Interested in Dr. Williams' research, Dr. Chamberlain contacted him to learn more about his findings. They would later form a strong collaboration with a primary goal to develop an accurate and reliable form of collecting family health data as well as providing effective interventions for families at high-risk for disease (R Chamberlain, personal communication, February 11, 2004).

Partnerships and collaborations between UCVG and the UDOH were also important in accomplishing that goal. Previous working relationships between Dr. Williams and UDOH staff in the Cardiovascular Disease Program opened up opportunities for further collaboration on the FHRP. Dr. Williams understood the importance of working closely with the public health sector in order to disseminate the program throughout the school system. He also recognized the advantage of utilizing the skills and resources of the UDOH and local health departments in developing and implementing effective follow-up interventions. Key individuals from each participating school district, high school, and local health department were invited to partner with the

UDOH to disseminate the program throughout the state. Without the support and collaboration from these individuals, the FHRP would have failed.

Collaborations between healthcare providers and public health were also critical for long-term program success. One of the major downfalls with the FHRP was its lack of support from healthcare providers as part of the follow-up component of the program. At the time of the FHRP, the potential for using family history to target screening and risk reduction messages was not being utilized in the medical care setting. Few healthcare providers or public health professionals were using this strategy to target at-risk populations. Although efforts were made to generate interest among healthcare providers, the lack of support from them to treat those with an increased risk of disease hindered the program's progress. Dr. Chamberlain stated during the assessment of the program, "One thing that's missing of course is the linkage back to the doctors that family members go to. The use of public health nurses or family-centered interventions is economical and probably effective but if it's not reinforced by a family doctor, it won't be successful" (R. Chamberlain, personal communication, February 11, 2004).

Program Materials and Methods of Delivery

The original HFT Questionnaire was developed by the National Heart and Blood Vessel Research and Demonstration Center at the Baylor College of Medicine, as part of a grant from the National Heart, Lung, and Blood Institute (NHLBI) to enhance risk reduction messages in required high school health education courses in Texas. It was used as a small part of a larger four-week curriculum designed to increase students' knowledge on the anatomy and functions of the heart and circulatory system, types of cardiovascular disease, risks associated with heart disease, and methods for preventing such diseases.³ The HFT was originally only used as a motivational tool to help students and parents communicate about the risk factors associated with cardiovascular disease such as smoking and diet (R Chamberlain, personal communication, February 11, 2004).

Dr. Chamberlain and his colleagues tested the curriculum program, officially entitled the Waco Family Health Program, from approximately 1980 to 1982. Data collection continued from 1983-1986, after implementation of the HFT in Utah, in four multi-ethnic cities with nearly 6,578 families from six schools in the Texas Waco

Independent School District.^{2,4,5} The HFT portion of the curriculum was an after-school project that parents and students could complete voluntarily. Upon completion of the project, the trees were sent to the Baylor College of Medicine where they were analyzed. If parents had previously elected to receive a copy of the analysis results, a personalized letter and the HFT were sent to them describing any risk the family may have for certain chronic diseases. Participating families were also invited to attend community classes on diet, exercise, and smoking cessation to reinforce learning and behavior change.³

At the time, little testing had been done on the validity of the HFT because of its original intent to only be used as an educational tool. However, some spot-checking of phone calls to approximately 100 participating Texas families had verified that the student's parents were involved in completing the HFT.⁴ Dr. Williams and his staff further assessed the tool's accuracy in collecting medical information by comparing the "incidence rate for 'heart attack' and 'stroke' by age and sex from 8,000 relatives of 600 Texas students in 1980, 1981, and 1982. The reproducibility of the age and sex specific incidence for these diseases as ascertained from the three independent sets of students was quite striking."⁴ These same rates were also compared to data from the Framingham study. Comparisons showed that data from the Texas students fell in the compatible range for similar age specific incidence rates of coronary diseases. Differences were noted in the incidence rates of strokes between the two studies; however, this could be accounted for by the large population of African American families living in Texas who had an elevated risk of stroke versus the lower risk of an all Caucasian Framingham population.⁴

Dr. Williams was interested in using the HFT as both an educational tool and means to collect family health data quickly and accurately. Data entry and analyses of the trees was an extremely painstaking, laborious, and costly process taking months to analyze a single tree. Dr. Williams and his team at UCVG solved the problem with data input and the lengthy time required for analysis, by developing optical scanner forms on which students could transfer data. This process also decreased the cost from \$25 per data analysis to less than \$10 per data analysis (this didn't include interventions for the high-risk families).^{2,4,5} Not only did this help the HFT evolve into a workable data

collection tool but it also enhanced the credibility of using family history as a means to personalize risk reduction messages.

Dr. Williams received three years of funding from the Thrasher Research Fund in 1982 to develop, pilot, and implement the “Medical Family History Questionnaire: A tool for screening and educating high school students.” Specific objectives of the proposal included development of: the HFT into a cost-effective tool; optical scanner forms to collect data; curriculum guide and trainings for high school teachers; computer programs for analyzing, interpreting, and reporting data; educational brochures for high-risk families; and continuing education materials for physicians working with high-risk families. The feasibility of obtaining a large amount of family history data would be tested by collecting “25,600 HFT questionnaires from 20 high schools in four Salt Lake County School Districts” during the three years, as stated in the original proposal.⁴

The accuracy of the data was also tested by comparing age and cause of death of 1,000 deceased persons as reported on the HFT with Utah death certificate records and the reproducibility of disease rates in high-risk families as compared to the general population.⁴ Additional validation studies comparing independent medical data from 1,273 relatives enumerated in HFT Questionnaires, showed the tool had 79% sensitivity, 91% specificity, 67% positive predictive value, and 96% negative predictive value for proband reports of coronary heart disease in relatives versus self-reported information by participating families.⁵

Rationale for the project focused on epidemiological studies of high-risk pedigrees in Utah families. Many of these studies had shown that numerous factors contributed to the occurrence of disease. For example, a review of the literature at the time of the original funding “sited 246 reported associations with coronary heart disease. Heart attacks, strokes, several major cancer sites, and risk factors for these diseases [had] all been reported to aggregate within families. Studies of twins, families with adopted children, ordinary families, and high-risk pedigrees [had] all revealed considerable familiarity for both coronary disease and stroke and for their major common risk factors including hypertension, hyperlipidemia, diabetes, and obesity.”⁴ Dr. Williams also noted that “some of this familial aggregation of risk may [have been] associated with genetic factors, others may be due to shared family environment. Even the expressions of genetic

factors [could] vary considerably depending upon associated environmental factors that interact with genetic predispositions.”⁴

Further population-based studies were reviewed using the Utah Population Database (UPDB). The UPDB contains millions of individual records from the Genealogical Society of Utah (Church of Jesus Christ of Latter-Day Saints) dating back to the 1800’s. Other records in the database included birth and death certificates from 1956 to present, driver’s license information, census records, Health Care Financing Administration (HCFA) records, and cancer registry data.⁶ With such a wealth of information, “familial predisposition to the occurrence of disease in the general population [could be] assessed [as well as studying] high-risk pedigrees to determine the details regarding genetic transmission, interaction with environmental factors, and important associated public health issues.”⁴ Specific examples of high-risk pedigrees were provided in the rationale section of the original proposal to further justify using a family history intervention to prevent or delay early disease in high-risk families.

There has been some criticism of the FHRP because it was implemented with a fairly unique population as compared to the rest of the United States. The religious background of the majority of the state’s citizens already encouraged recording detailed family histories and access to generations of genealogical records are readily available to all citizens. Family pedigrees in Utah are also typically larger than in other states and many families live in the same area for generations making diagnosis and treatment of familial disease trends easier for researchers. However, data from Texas students participating in the HFT project show similar results when compared to Utah data.⁴ This may quiet any concern that similar programs could only work in Utah and wouldn’t be generalizable to other populations.

The original expectations for piloting program materials were far exceeded by actual results. Only 600 students in two high schools were expected to participate during the first year of development and pilot testing. However, this innovative program generated such enthusiasm that the pilot project was expanded to include over 1,000 students in seven high schools. During the pilot program (Spring 1983) and first and second semesters of implementation (Fall 1983 and Spring 1984), 814 families were identified as high-risk for various diseases. Of these high-risk families, 87% had

received follow-up interventions from a public health nurse and 64% had a physician referral made. Detailed statistics from the pilot program can be found in Appendix B.

The pilot program was necessary for feedback on the development of program materials. Three different versions of the HFT and optical scanner forms were developed and tested with participating schools during this time. Instructions and lesson plans were also tested during the pilot phase of the program to ensure that teachers could adequately teach the material content and complete the HFT activity with minimal communication between program planners. Clerks, genealogists, data input operators, computer programmers, and statisticians working with UCVG developed computer programs to read the optical scanner forms and report results during that same timeframe.⁴

The HFT was designed to collect three generations of family medical history. Its deliberate size, 2' x 3' or that of a roadmap, was intended to catch one's attention and encourage the entire family to participate in collecting information. The information included lifestyle factors such as smoking, alcohol use, obesity, and exercise patterns as well as certain disease conditions, for the siblings, parents, aunts and uncles, and grandparents of 10th grade students enrolled in required high school health education classes throughout the state. Specific disease conditions on the HFT included cardiovascular disease, stroke, breast and colon cancer, other cancers, high blood pressure, high blood cholesterol, and diabetes. The condition "other cancers" was removed from the HFT in 1996. In 1995 hip fractures, asthma, and Alzheimer's disease were also added to the HFT. Refer to Appendix C for the HFT.

The delivery method of the program placed a huge burden on both UDOH staff and school personnel. Program materials were sorted by hand and then delivered and picked up from each participating class by UDOH staff. In later years of the program, volunteers from the Golden Years Senior Center helped alleviate some of the burden on UDOH staff by organizing program materials into individual classroom packets. Participating teachers were also required to re-sort the materials once students had completed the HFT, to find any mistakes that might interfere with data analysis, before arranging pick-up times with UDOH staff. With 55 high schools and 284 teachers participating at some point in the program, the task of organizing and collecting materials

became overwhelming at times. Refer to Appendix D for a list of participating school districts and high schools.

Teachers were encouraged to use the HFT as the focus of a four-day curriculum (not necessarily four consecutive class periods) on heredity diseases, risk factors, and interventions to reduce one's risk for chronic disease. A curriculum guide was written and updated periodically by FHRP staff with little input from participating health education teachers. It instructed teachers to review medical terms and the medical pedigree concept with their students during the first class period. Day two consisted of teaching students how to fill out the HFT Questionnaire. A letter explaining the program, the HFT, and a parental/guardian consent form were also given to students as a homework assignment to have signed and completed by the following class period. Students were then able to transfer the information from the HFT to the optical scanner forms during day three of the curriculum. On the fourth day teachers were instructed to base their lessons on ways to counter familial predisposition with healthy lifestyle choices and interventions.⁷ Refer to Appendix E for a sample of the school curriculum.

After collecting information for the HFT Questionnaire, students transferred the data onto optical scanner forms and filled out a demographic survey, completed on day three of the curriculum. This allowed researchers from UCVG to analyze the information and determine the disease risk for each family or the Family History Score (FHS). The FHS was defined by 1) the number of affected 1st degree relatives (0, 1, 2 or more) and whether their age of disease onset were early (before age 55) or late (after age 55) and 2) using a quantitative family history score either as a continuous variable or by selecting cut-points to define particular groups. The equation for computing the ratio is:

$$\text{If } |O - E| > \frac{1}{2} \text{ then } FHS = \left(\frac{|O - E|}{E} - \frac{1}{2} \right) \frac{|O - E|}{O - E} \quad \text{or,}$$

$$\text{If } |O - E| < \frac{1}{2} \text{ then } FHS = 0$$

where O is the observed number of family members with a particular disease and E is the expected number of family members with a particular disease calculated by multiplying

the age and sex specific person-years of experience of the family by the age and sex specific incidence rates of the general population. The FHS can help to distinguish whether a family is at average risk or an increased risk for disease. A FHS can range from very strongly positive ($FHS \geq 2.0$), strongly positive ($1.0 \leq FHS < 2.0$), positive ($0.5 \leq FHS < 1.0$), average ($-0.5 \leq FHS < + 0.5$), and protective ($FHS < -0.5$). In addition to the FHS, at least two members of the family had to be affected with the disease to be considered “high-risk”; this is due to the instability of the FHS in very small and/or young families. Only families with a $FHS \geq 1.0$ were considered “high-risk” and referred into the FHRP.^{2,5, 8, 9, 10}

Students were encouraged to participate regardless of whether or not they were a blood relative to their parents, aunts and uncles, or grandparents. Statistical analyses were calculated separately for each parent, which helped find high-risk families even if the student was not a blood relative. This also accounted for any risk the family may have for disease based on shared environmental factors. Computer generated reports were then mailed directly to each student’s family, regardless of whether or not they were considered as “apparent strong tendency” (as worded in the computer generated reports) or in other words “high-risk”. These detailed reports summarized family risk, if any, for diseases listed on the HFT. The reports also summarized any lifestyle changes that could be made to decrease family members’ risk of developing the diseases. Refer to Appendix F for an example of the analysis report. Data entry, processing, and report generation took months at a time to complete. Not only was this financially costly but it was also a distraction to the intent and message of the program, to prevent or delay disease onset.

Legal Issues

Parents or guardians were required to give consent for their student to participate in the program before data was collected. Three participation options were given to parents/guardians and students. Refer to Appendix G for a comparison between students’ participation rates and the level of consent chosen by parents/guardians. Option 1 gave students consent for full participation in the program (81% of participants choose this option). This included a personalized computer evaluation of the student’s tree, permission for UDOH, local health department or University of Utah representatives to

contact the family, and permission to store name, address, and phone number in confidential research files at the University of Utah Medical Center for further research. Option 2 allowed for partial participation that included permission for the student to complete the HFT but receive no computer evaluation, follow-up visits or further contact (12% of participants). However, data analysis from the students' HFT was stored anonymously on research files at the university. Option 3 was nonparticipation in the program (7% of participants).^{9, 10} Students who chose Option 3 were given alternate assignments to complete. Nonparticipation had no effect on the student's grade so long as alternate assignments were completed on time. Refer to Appendix H for the parental/guardian consent form.

Training Issues

Participating health education teachers received training on how to collect data for the HFT before the program was implementation into the schools. During in-service trainings teachers received curriculum materials such as lesson plans, overheads, optical scanner forms, and trees for their students at no cost to themselves or the school districts. Refer to Appendix I for an example of the in-service training materials. The in-service trainings were one-day voluntary meetings conducted by personnel from the UDOH. Teachers were provided with the option of additional one-on-one training from FHRP staff as needed throughout the school year.

Similar in-service trainings for public health nurses took place at local health departments. UDOH staff, and occasionally accompanied by Dr. Williams as well, provided instruction on how to effectively use the FHRP nursing protocols and standards of care. Demonstrations of how to use medical equipment for assessments, such as blood pressure checks, were also reviewed with nurses. It was intended that once the trainings were completed, nurses or school coordinators, as they were called, would be on hand at each local health department to help participating teachers and families with any problems that arose during program implementation.

As the program grew, new teachers and local health department nurses were given little if any training from FHRP staff and previous participants were left to train newcomers without support from the UDOH. This not only created a lack of enthusiasm

among teachers, but also decreased participation rates among their students. And some high-risk families received inadequate interventions from public health nurses because of the lack of support and enthusiasm for the program in certain health districts.

Training efforts were also made with physicians working with high-risk families. Continuing medical education (CME) units were available to health care providers through Grand Rounds, a self-study course, and set of videos. Dr. Williams and other medical experts in breast and colon cancer, diabetes, coronary heart disease, high blood pressure, and familial trends developed these materials. Additional letters, advertisements, and information on available training materials were sent to health care providers around the Wasatch Front and to the Utah Medical Association in order to generate interest and support for the program.

Interventions

The intervention component of the FHRP centered on family-based activities. Family-based interventions were highly effective during the early years of the program. This type of intervention allowed assessment of the entire family structure, taking into account not only medical history but social structure, lifestyle behaviors, and family dynamics. Only families who were found to be at “high-risk” from the HFT analyses were recommended to the FHRP for further follow-up and intervention. However, not all of the high-risk families were referred into the program. UCVG did keep the names and contact information for some of the families found to be at extremely high-risk for coronary heart disease and high cholesterol to include in their own studies and research, such as the MED PED program. The computer analyses for the rest of the high-risk families were then sent to the UDOH where FHRP staff coordinated with local health departments, in the community where the family lived, to have public health nurses provide further assessments, education, and referrals. Follow-up interventions had to begin within six weeks from the time nurses received the family’s contact information (J. Ware, personal communication, January 27, 2004). Nurses were also responsible to follow-up with high-risk families in their health district at least once a year and then report results back to the UDOH.

Public health nurses initially contacted high-risk families by telephone to determine if and when an in-home visit was feasible. Nurses were also instructed to review the family's tree analysis with them and to determine family members' risk awareness during this first contact. FHRP nursing protocols were developed to ensure verification of contact and validation of HFT analysis with all high-risk families. Refer to Appendix J for the FHRP nursing protocols. If permission was given during the initial phone call, nurses scheduled in-home visits with families to provide education on risk reduction and lifestyle changes that could prevent or delay chronic illness. In-home visits could also consist of further medical assessments, such as checking blood pressure or blood glucose levels, and if necessary referral and encouragement to see a physician or other healthcare provider. If an in-home visit wasn't feasible, either due to time constraints, inability to contact families or refusal, nurses were instructed to send the appropriate educational brochures, questionnaires, and medical referrals by mail. The benefits of home visits were very advantageous. However, as funding and time constraints were placed on both the UDOH and local health departments, fewer families received the care they needed or that program planners had intended. Changing family dynamics throughout the last 20 years had also placed great burdens on completing these same intervention activities.

Dr. Williams and qualified personnel at the UDOH also developed disease-specific standards of care to help ensure nurses gave proper recommendations to each high-risk family during follow-up visits. These protocols or guidelines taught nurses how to assess family members' current knowledge of the disease(s) they or other family members were at risk for, explain risk factors for that specific disease(s), and identify healthy lifestyle behavior changes that could help to prevent or delay disease onset. Specific objectives for each protocol were to ensure high-risk families could identify risk factors for the specific disease or condition; set appropriate goals for behavior change to decrease risk and enhance prevention; describe and/or perform recommended screening practices; seek appropriate medical care; and anticipate additional follow-up components of the FHRP. Educational brochures and other teaching materials were available to supplement the standards of care protocols. Refer to Appendix K for an example of a protocol in the standards of care manual.

Other follow-up interventions included classes on diet, exercise, stress management and smoking cessation programs, free cholesterol and blood pressure screenings, and if necessary referral into other UDOH and UCVG programs. Physicians were also incorporated into the follow-up component of the program. Letters from local health departments were sent to the high-risk families' health care provider, if prior permission from the family had been obtained, stating their patient(s) were at risk for a specific disease. Refer to Appendix L for the letter to physicians. Despite efforts to incorporate physicians into the follow-up component of the program, training materials were rarely used and often high-risk families reported to local health departments that health care providers refused to treat them if they did not have any presenting symptoms of the disease(s).

The FHRP was an innovative, cost-effective, and highly successful program. Although the UDOH dropped the program in 1999, data from Health Family Trees were collected by UCVG until Spring 2002. An astounding 80,611 useable trees were collected during this 20-year span. This amounts to over 1,138,474 relatives, including students' 1st and 2nd degree relatives, from 151,188 Utah families (paternal and maternal sides were collected separately because they are genetically unrelated).^{9, 10} A total of 8,546 families were identified as high-risk for a particular disease and on average 90% of the families had some form of contact from a local health department public health nurse. Over 60% of the contacts were in-home visits with the families (J. Ware, personal communication, January 27, 2004). Refer to Appendix M for further explanation of the statistics for the number of individuals at high-risk for chronic disease(s) per year. It should be noted that some of the data from the FHRP might differ from other sources. Data was collected and stored by hand for a number of years and as program planners transferred data from paper to electronic sources, some of it was lost or skewed. The above statistics are the most accurate available to the UDOH.

The success of the program generated worldwide interest. Inquires about the utility of using the HFT to identify and intervene with high-risk families were received from Germany, Russia, Japan, South Africa, Hungary, France, Sweden, and Canada. Program planners received additional contacts from universities and state health departments in New Jersey, Texas, Oregon, Maine, Minnesota, North Carolina,

California, Florida, and Iowa. The attention climaxed upon awarding of the Secretary of Health's National Award of Excellence in 1986 to the FHRP as a "distinguished community health promotion program" by the Department of Health and Human Services. The FHRP was also a semifinalist in the Innovations in State and Local Government Awards, an awards program of the Ford Foundation and Harvard University John F. Kennedy School of Government, in 1986, 1988, and 1990.

Evaluations

In order to assess the effectiveness of the program, a long-term follow-up study was conducted by the UDOH on high-risk (cases) and average-risk (controls) families. The evaluation was completed over a 10-year period and followed the same cohort of families throughout this time. The evaluation method was designed to measure behavior change or modification in both case and control families. Behavior changes that were evaluated included whether or not family members received annual medical exams, blood pressure checks, cholesterol tests, monthly breast self exams, mammograms, routine exercise, decreased salt, fat, and dietary cholesterol consumption, increased fruit, vegetable, and grain consumption, weight loss, and quitting smoking.

The surveys were also designed to reinforce the education provided by public health nurses to establish preventive health habits. Previous pilot surveys were found to be quite lengthy with low response rates. As a result the Health Status Surveys used for the evaluations were designed with only 34 questions to make completing them quick and easy. Refer to Appendix N for an example of questions from the Health Status Surveys.

A baseline Health Status Survey was sent to a cohort of case and control families in 1986. The cohort was comprised of participating families from Spring 1983 to Spring 1985 and was stratified according to school district and semester. Case and control families had completed a HFT during this timeframe (Spring 1983 – Spring 1985) and given full consent to have additional contact from FHRP staff (Option 1). The cases for the baseline survey had received follow-up interventions with public health nurses while the controls received no such interventions. Case samples were randomized by the UDOH while staff from UCVG randomized control samples. Of the cases who received the Health Status Survey, 366 families or 53.7% completed and returned it to the FHRP.

Four hundred twenty-one control families or 62.7% also completed and returned the baseline survey. Approximately 29% of cases and 20% of controls were classified as non-respondents. Refusal rates for case and control families were low, around 9% for each group.

The Health Status Survey was again sent to the same cohort of case and control families in 1987. Three weeks after the initial mailing of the survey, thank you letters and reminder postcards were sent to families according to whether or not they had completed and returned the survey. A second mailing of letters and surveys were sent to all non-respondents four weeks later. Four weeks after the second mailing, certified letters and surveys were sent to the remaining non-respondents in the hope that the majority of cases and controls would participate in the follow-up evaluation. Two hundred sixteen case families and 263 control families completed and returned the first follow-up survey.

Program planners originally intended to survey the cohort of families each year for a total of four years; however, a second follow-up survey wasn't completed until 1990. The case and control families that participated had previously completed both the baseline Health Status Survey and first follow-up survey. Then in 1996 a third and final survey was sent to the cohort of case and control families. The surveys were sent to families who had completed one or both of either the first or second follow-up surveys as well as the baseline survey. Over 80% of the high-risk families participated in the final survey. Similar participation rates were found for average-risk families, roughly 76% completed and returned the third follow-up survey. Refusal and non-respondent rates for both the case and control families combined were low, 2% and 5.5% respectively. Graphs that show the percentages for each survey question from 1986-1996 can be found in Appendix O.

Family High Risk Program staff periodically conducted teacher and student satisfaction surveys throughout the program although no data was available to the UDOH. They also conducted two small preliminary pilot evaluations in 1996. Program staff were interested in evaluating the current program to see if high-risk families were receiving the same quality of interventions at the end of the program life as compared to those high-risk families who had participated in interventions during the early years of

the FHRP. The first evaluation was conducted by telephone survey with 20 high-risk families identified in 1994, 1995, and/or 1996. These families were picked according to the health district in which they lived in order to get a picture of how the program was functioning throughout the entire state. The results of the telephone surveys were to be used in guiding the future direction, and if necessary additional evaluations, of the program.

Review of the survey results showed that few if any high-risk families were receiving interventions from local health department nurses. The second pilot evaluation, conducted by telephone survey with 19 public health nurses, showed similar results when compared to the first pilot evaluation. Most of the high-risk families weren't even receiving an initial telephone contact from a public health nurse, or any type of in-home visit and additional education. Refer to Appendix P for the pilot telephone surveys and results. It became apparent that the current state of the FHRP was not functioning as it had been designed originally. Major revamping and evaluation was needed in order to continue the program. However, funding was eliminated before further recommendations could be developed.

Data were collected throughout the program on each student's level of parental consent (participation), school district and high school attended, and demographic information such as parent's education and income levels. Students who completed the HFT and the appropriate optical scanner forms also provided program planners with a written survey. The survey measured comparisons between a student's level of participation in the program and their parents' education and income levels were made, although no formal review of the data was conducted. Data on the level of participation and parent income and education levels were provided to the UDOH by UCVG and can be found in Appendix Q.

The Cardiovascular Genetics Research Clinic conducted an 18-year follow-up study with a proposed 200 high-risk and 200 low-risk families; currently only 125 high-risk and 125 low risk families have been contacted. The high-risk families represented the top 20th percentile of coronary heart disease family risk while the low-risk families represented the bottom 20th percentile of CHD family risk, in participating families from 1983-1987. Both groups were selected so that all parents of the student were unaffected

by any type of cardiovascular disease as reported in the initial data collection. Families were then re-contacted by telephone in 2001-2002 to determine current reported disease status on these previously reported unaffected parents. They were asked several questions on current and past health history such as weight, height, and age (to determine Body Mass Index), blood pressure, diabetes, activity level, medications taken, and targeted questions on CVD.¹¹

Jason V. Slack, a candidate for the Doctor of Philosophy degree, designed and conducted the study but has been unable to complete it at this time due to active military duty. However, preliminary data analysis by UCVG staff has shown that the significant relative risk for CVD between the high and low-risk families is 4.0 for all ages combined.^{9, 10} This helped to further validate the current FHS used in data analysis as a reliable formula for predicting future disease in high-risk families. Final results will be available upon completion of the study.

Funding

As stated earlier in the report, Dr. Williams and his team at UCVG were able to reduce the cost of collecting data from the HFT dramatically. Cost for each high-risk family was approximately \$27.⁵ This included the cost of data processing, report generation and mailing, as well as in-kind donations from local health departments and the UDOH Cardiovascular Program to provide follow-up interventions. Cost for students completing the HFT but not receiving follow-up interventions was less than \$10 per student, which included printing, distribution, and analyses of trees. The costs for both high-risk and average-risk families compare favorably to other types of behavior-modifying programs. Additional information on the cost of the program is available in UDOH budget records found in Appendix R.

The largest barrier facing any program is funding and for the FHRP this was no exception. The FHRP was a new and innovative way to prevent chronic disease and little national support was given to program planners to enhance and carry-on such activities. Lack of funding prevented many issues from being addressed and was at the root of many of the problems mentioned in the report. To further illustrate the problem, former FHRP staff directly attributed lack of funds to inadequate evaluations, poor participation rates

among some high schools, lack of enthusiasm within local health departments and the UDOH, inadequate staffing levels, weak collaborations with health care providers, and ineffective intervention strategies in later years.

The decision to end the FHRP was attributed to lack of funding. Program staff had been desperately trying to re-asses the FHRP throughout the mid-1990's but were unable to conduct thorough evaluations to learn what needed to be changed. Two pilot surveys were conducted with high-risk families and public health nurses but sample sizes were small and provided few ideas for future recommendations. Dr. Williams, program "champion", was no longer alive to generate support for the program and as such, little interest at the UDOH to pursue other funding sources sent the program spiraling downward, eventually leading to its demise.

Future Recommendations

This section of the report describes future recommendations for those wishing to implement similar programs to identify and intervene with families at risk of chronic disease. These recommendations are based on the challenges, successes, and experiences of the UDOH. They are to be used as a guide to develop, implement, and evaluate family history projects within a public health setting. Numerous key players from the FHRP have provided insight into the recommendations.

Program “Champion”

Although there are many components contributing to the success of the program, perhaps the most critical was Dr. Williams himself. Nearly every individual who was interviewed throughout the development of the report stated the success of the program was a direct result of Dr. Williams’ enthusiasm and energy. He took upon himself the role of program “champion” and worked tirelessly to identify and ensure that every high-risk family in the program received adequate care. He advocated the use of family history tools and the FHRP to colleagues and public health organizations at national, state, and local levels.

The energy, enthusiasm, and vision that Dr. Williams personified are crucial in developing a new family history intervention. A “champion” willing to push through challenges is an absolute must to generate the needed support from community partners. This person must also serve as the driving force behind national support, including financial, vital to developing a program with this magnitude. The “champion” must be skilled in building and maintaining collaborations at the national, state, and local levels both within the medical and public arenas. Participation among community partners and families will fail unless there is an individual willing to take on this role.

Partnerships and Collaborations

Another aspect of the FHRP that led to its success and which is crucial for the development of a similar program, is the impressive partnerships between the University of Utah, UDOH, local health departments, and school districts throughout the state. These unique collaborations helped bridge the gap between research and public health

practice, enabling program planners to capitalize on various resources and expertise throughout the state. Although difficult to maintain at times, such collaborations are important for the needed financial support and buy-in required to develop this type of program. Attention should be given to developing strong collaborations with national organizations as well, something that was lacking in the original FHRP.

Appropriate partnerships for a future program should include a university or research setting, state health department, health care providers, local chapters of national health organizations such as the American Cancer Society or American Lung Association, and depending on the avenue of distribution, school districts and local health departments. Perhaps the most important partnership among these is that between the university and state health department. University settings often have the statistical and medical expertise needed to determine risk and provide justification for such endeavors. However, in turn, public health organizations often have a greater understanding of the processes necessary for the development of targeted interventions than do research oriented groups. This partnership is also important because it is the most likely avenue for generating the program “champion”.

As noted earlier in the report, the healthcare system will continue to be the weak link in similar programs unless careful consideration is given to developing partnerships within these systems. This does not mean that health care providers alone are responsible for behavior change in high-risk families. Public health also has a responsibility to translate risk into tailored interventions that are culturally diverse and sensitive. By working together to reinforce the same risk reduction messages, health care providers and public health experts can help families begin to understand the importance and urgency of following appropriate medical recommendations and/or lifestyle modifications.

One strategy to involve health care providers in future programs might be to develop an advisory board with key individuals from surrounding hospitals, healthcare organizations, and medical schools. For example, in Utah, it might be appropriate to invite representatives from Intermountain Health Care (IHC), Deseret Mutual, Health Insight, United, Blue-Cross Blue-Shield, the Utah Medical Association, and the University of Utah to serve on an advisory board. The advisory board would be responsible for identifying potential roadblocks in utilizing healthcare providers in the

interventions as well as to develop strategies for overcoming them. Only when providers are supportive of this type of program will long-term success be seen.

Program Materials and Methods of Delivery

The delivery method of the FHRP was time-consuming for UDOH and UCVG staff as well as participating teachers and families. One solution to the problem could be to develop a computer or Internet-based HFT, similar to the family history tool being developed by the Centers for Disease Control (CDC), entitled Family Healthware.¹² By utilizing current technology, an easily modifiable HFT could be developed and implemented in different settings throughout the nation. Features that allow the flexibility of adding or deleting diseases and lifestyle risk factors on the HFT might provide new insights into risk reduction strategies. Language and cultural barriers could also be addressed because the ease of translating the HFT and analyses reports would be instantaneous if the program was computer-based rather than paper-based.

An electronic version of the HFT would also make the program more cost-effective for identifying a greater number of families at risk for disease. Cost estimates for an Internet-based HFT program range from \$1 to \$3 per family and approximately \$5 per high-risk family (when administered through the school setting).¹³ Additional funds could then be allotted to developing new public health intervention strategies for high-risk individuals. These savings would also allow program planners to use funds once needed for program delivery expenses (printing costs of the HFT and optical scanner forms as well as mileage costs to deliver and pickup trees from participating schools), to explore additional avenues of program delivery rather than just through the school system. Settings such as physician offices, cancer or diabetes clinics, medical or public health programs at universities, and worksite wellness programs may be interested in using an Internet-based program. These options could be explored easily, with less money, and on a much wider basis with an Internet-based HFT.

Recommendations to develop an Internet-based HFT and explore additional avenues of delivery could also theoretically help to disseminate the program across the country. If a similar program is developed again, program planners must allot adequate funds and resources for implementing programs in various settings to further demonstrate

the usefulness of family history as a public health intervention. Data from the settings could then be used to continually refine program materials to fit the needs of diverse populations. More attention should be given to developing culturally sensitive risk reduction messages and tailored interventions. The parental consent options, high school curriculum guide, standards of care guidelines, nursing protocols if appropriate, computer generated analysis reports, and evaluation tools are all materials which need major revisions to reflect current knowledge of cultural beliefs, medical practices, screening recommendations, state education requirements, and any applicable laws before implementation of the program again.

Legal Issues

An Internet-based program could also provide solutions to the legal constraints associated with collecting family history information. Privacy and confidentiality issues were, and still are, a major concern for program planners. Currently the State and Federal Educational Rights and Privacy Acts (FERPA) and the Health Insurance Portability and Accountability Act (HIPAA) are potentially the largest legal barriers for a future program, if implemented in high schools again.^{14, 15} Re-introduction of a program in high schools is severely limited by FERPA and HIPAA laws, which provides further justification for exploration of program delivery into additional settings.

An Internet-based HFT would allow researchers to collect data anonymously as well as control who has access to the information. Students could complete the HFT at home or at school computer labs without having anyone else see their health history. Passwords and safety features could be built into the Internet version to further protect participants' confidentiality. Consent forms could also be posted on the Internet version so all participants had access to and understood their level of participation. Interventions could also be adapted on-line to prevent problems with invasion of privacy during home visits and phone calls from local health department nurses.

Lyle Odendahl, Assistant Attorney General at the UDOH, recommended that although health history is not included in FERPA, prior written consent should be obtained before program participation. He further recommends updating the parental consent form to reflect FERPA and HIPAA requirements as well as detailing what types

of contact or further research may be conducted with the families. Consent would also need to indicate the process used to ensure confidentiality of information collected as well as what organizations own the data and will have future access to it. Working with the State Office of Education and Institutional Review Board departments at both the UDOH and University of Utah would ensure appropriate approval processes are followed and legal issues were addressed.

Training Issues

Frequent and more intensive trainings will be required of future participating teachers and nurses, or whatever group is responsible for program distribution and follow-up. Trainings should focus on teaching these groups the importance of collecting baseline health data and then using the information to intervene with lifestyle modifications. Yearly trainings would orient new teachers and nurses to the program while continuing to generate support from participating individuals. Inviting current teachers or nurses in the program to present ideas on how to use the curriculum or protocols could help generate buy-in and interest. Problems with program logistics could also be addressed during trainings to continually update curriculum materials and procedures to make the program more effective.

These trainings require a lot of time and staff support. Exploring alternative ways of training those involved with the program should be considered. For example, video or web-based training modules might be developed as cost-effective alternatives to group or individual in-service meetings. These modules could also be used by individuals around the country instead of only those within the state where the HFT program has been implemented. Training options should be explored only after thorough pilot testing and assessments are conducted with potential user groups.

Interventions

Recommendations for new interventions should still focus on strengthening the entire family structure. Interventions would be used to teach families how to maintain behavior change such as regular exercise or eating a healthy diet, follow appropriate screening guidelines, build a support system, and apply other tailored messages. Home

visits and in-person contacts might not be possible in today's society but perhaps social marketing techniques and improved understanding of behavior change can be applied to develop a more effective follow-up component.

Allocating funding for extensive assessments of high-risk families is recommended as the first step in developing a program that uses family history as a tool to identify and treat families at risk for disease. Families should be actively involved in each phase of program development. Insights from the intended audience could be used to design an attractive HFT, develop culturally sensitive program materials or messages, and help program planners understand what interventions are most feasible and effective for today's busy family. These types of activities could also help program planners understand the ethical, legal, and social issues associated with this type of program. High-risk families might not receive adequate follow-up for reasons unknown to program planners, but by conducting extensive assessments with different groups they can begin to identify and address these barriers in the intervention component of a new program.

Evaluations

Evaluations for a new program should be developed using current knowledge of health promotion models and theories and include both impact and process evaluation. Throughout the assessment of the FHRP, thorough planning and adequate funding for a strong evaluation component was identified as a weakness. Program planners who designed and conducted the original Health Status Surveys should be commended on their efforts and care in measuring behavior change but with outside barriers like funding and staffing levels facing them, their efforts were hindered at times.

Long-term cohort studies on high-risk and low-risk families should be conducted to measure behavior change. The studies should follow more than one cohort group. For example, every four years a new cohort of families could be added to the evaluation plan and then surveyed annually over a specified period of time along with the other cohort groups. This would provide data on the effectiveness of the interventions from families throughout the life of the program, not just families from the beginning years. Evaluations on the program processes should be planned before program implementation to continually adapt the program to the needs of participants.

State-of-the-art technology should be used to explore options for delivery of the evaluations. Today, program planners have the ability to collect data electronically by email or Internet-based surveys. Collecting data in this manner not only yields instant results but is also safer in that it can be stored on computer and accessed only by certain individuals if necessary. Data would also remain consistent and accurate if collected and stored electronically.

Comparing results from these evaluations with data from other reliable surveillance systems might also help in fully understanding the impact of the program. For example, results from Utah participants could be compared with data from Utah's Indicator-Based Information System for Public Health (IBIS-PH), Youth Risk Behavior Surveillance System (YRBS), and/or Behavioral Risk Factor Surveillance System (BRFSS) to verify behavior change as reported in the evaluation surveys. This would also verify the number of high-risk families identified by the HFT as compared to state and national rates of disease, furthering the justification for use of family history tools in disease prevention and health promotion.

Funding

Exact costs of such a program are extremely hard to predict. It is recommended though that significant funding be allocated to the pilot and first year of implementation. These years are crucial for establishing and revising a well-planned program. Extensive assessments with different populations will need to be conducted during the pilot year in order to develop appropriate materials and intervention strategies. Different channels of delivery will also need to be explored and researched during this time to help make the program useful for large numbers of people. Evaluation methods will also require substantial funding to develop effective plans for delivery and assessment. Staffing levels will need to be adequate to support the many partnerships and collaborations associated with a program of this magnitude.

Recommendations for this area are hard to define. Generating funding from both national and state organizations is a difficult and time-consuming task with few rewards. However, with the development of new initiatives focusing on genomics and family history at the national level, funding sources should be available for program planners

interested in re-designing the FHRP in the coming years. Careful planning must ensure adequate funds are obtained to follow recommendations such as extensively assessing the target audience, developing effective interventions, and conducting appropriate evaluations. Only when program planners are able to prove the efficiency and effectiveness of the program by following these recommendations will the needed financial support continue to be generated.

Significant barriers will be encountered as these recommendations are used to develop a “new and improved” program. However, with thoughtful preparation and collaboration, progress can be made in designing and implementing a successful program similar to the FHRP. Family history is quickly gaining momentum as an effective tool to identify and prevent or delay early disease onset. Public health needs to be ready to respond to this initiative and utilize knowledge from programs such as the FHRP in health promotion and education. The recommendations made throughout the report have been written to serve as a building block in this process.

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³ Baylor College of Medicine National Heart and Blood Vessel Research and Demonstration Center (n.d.). *WACO Family Health Program*, (pamphlet).

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- ¹⁴ Federal FERPA (n.d.). Retrieved January 29, 2004, from <http://www.usoe.k12.ut.us/LAW/PDF/FERPA%20Summary.pdf>
- ¹⁵ United States Department of Health and Human Services Office for Civil Rights – HIPAA (last revised May 7, 2004). Retrieved June 3, 2004, from <http://www.hhs.gov/ocr/hipaa/>